



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
September 21, 2015**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates, Cofounder, VP of Operations, Pathology Solutions

Elizabeth K. Bell, BS, Public Member - Individual or Family Member with Autism Representative; Volunteer and Independent Contractor with Autism Speaks

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute

Thomas V. Macchiaverna, MA, Public Member Representative; Special Education Teacher

Dana E. Spett, MSW, Autism Organization Representative; Founder/Executive Director, Pony Power Therapies

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Associate Professor, Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

*Denotes Council Chairperson

Absent

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

NJ Department of Health (DOH) Attendees

Martin T. Zanna MD, MPH
Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, M.Ed., MBA
Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research
Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant
Scientific Planning Consulting

Sandra Howell, Ph.D., NJDOH, Division of Family Health Services, Autism Registry

Rachel Hammond, JD, NJDOH Ethics Officer

Public Attendees

Gerard Costa, Ph.D., Center for Autism and Early Childhood Mental Health at Montclair State University and Principal Investigator, NJ ACE Coordinating Center

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Eileen McKeating, Ph.D., Research Associate, NJ ACE Coordinating Center

Cecilia Feeley, Ph.D., Rutgers Center for Advanced Infrastructure and Transportation (CAIT)

Jill Harris, Ph.D., Children's Specialized Hospital

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:05 PM and welcomed everyone with a special welcome to the five new members. All members introduced themselves.

II. Public Meetings Act Announcement- Dr. Eggerding read the Public Meetings Act, followed by roll call.

III. Approval of the May 18, 2015 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the minutes. MOTION by Ms. Goldfarb to approve the minutes was seconded by Ms. Bell. No discussion.

MOTION to approve the minutes was passed with three in favor and six abstentions.

IV. Ethics Presentation-Rachel Hammond, JD, Ethics Officer

Ms. Hammond discussed ethical issues related to the role of Council members as Special State Officers. In addition to the State's Code of Ethics the Council's Code of Ethics at <http://www.state.nj.us/health/autism/index.shtml> defines specific requirements as related to the Council. She referred members to the State website at <http://www.nj.gov/ethics/> as a resource and encouraged members to contact her (609-292-1447) if they have questions.

V. Approval of 2016 Council meeting calendar

Dr. Eggerding called for a motion to approve the 2016 Council meeting calendar. MOTION by Dr. Wang to approve the calendar was seconded by Dr. Dreyfus. No discussion.

MOTION to approve the calendar was passed with all in favor.

VI. Autism Registry Presentation-Sandra Howell, Ph.D.

Dr. Howell provided a brief history of the NJ Autism Registry for the benefit of the new Council members. She then proceeded with a description of the benefits of the Registry including linking families to services and using data to describe the population in terms of demographics, diagnosis type and other characteristics to plan for future services and policies. Members were engaged throughout the presentation with questions and comments.

For additional information: http://www.nj.gov/health/fhs/sch/autism_registry.shtml

VII. Continuation funding for 2012 and 2014 grantees

The Council was requested to consider continuation funding for five 2014 grants, one 2013 grant and two 2012 grants.

Grant # CAUT14APL014

Dr. Eggerding called for a motion to approve Grant # CAUT14APL014, *Mitochondrial and Channelopathy Disorders and Dysfunction in Autism Spectrum Disorders: Genotypic and Phenotypic Correlations* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT14APL014 for year two continuation funding was seconded by Ms. Spett.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred. A discussion ensued concerning the science of the grant and measuring progress. Dr. Costa and his staff provided additional information about the grantee's progress. He stated as a result of the increase in the number and diversity of grants he has posted positions for both a biomedical and a behavioral consultant to assist his staff in evaluating progress. Dr. Eggerding noted that all grants were awarded based on rigorous reviews by both the Scientific Merit Review Panels and the Scientific Advisory Committee.

MOTION to approve continuation funding for Grant #CAUT14APL014 was approved with eight members in favor and one recusal.

Grant # CAUT14APL018

Dr. Eggerding called for a motion to approve Grant # CAUT14APL018, *New objective autism inventory to quantify peripheral plasticity during standardized ADOS-2 social exchange* for year two continuation funding.

MOTION by Ms. Bell to approve CAUT14APL018 for year two continuation funding was seconded by Ms. Goldfarb.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT14APL018 was approved with seven members in favor and two recusals.

Grant # CAUT14APL028

Dr. Eggerding called for a motion to approve Grant # CAUT14APL028, *A human stem cell-based model to study autism-linked endoplasmic reticulum stress and initial testing of therapeutic strategies* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT14APL018 for year two continuation funding was seconded by Ms. Bell.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT14APL028 was approved with seven members in favor and two recusals.

Grant # CAUT14APL029

Dr. Eggerding called for a motion to approve Grant # CAUT14APL029, *Analysis, validation and dissemination of a paratransit travel and mobility assessment for adults on the autism spectrum* for year two continuation funding.

MOTION by Ms. Goldfarb to approve CAUT14APL029 for year two continuation funding was seconded by Ms. Bell.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT14APL029 was approved with seven members in favor and two recusals.

Grant # CAUT14APL031

Dr. Eggerding called for a motion to approve Grant # CAUT14APL031, *Metabolomic analysis of neural precursor cells derived from Autism iPSCs and their response to environmental stressors* for year two continuation funding.

MOTION by Ms. Bell to approve CAUT14APL031 for year two continuation funding was seconded by Ms. Spett.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred. A member requested additional information regarding progress given the lack of specifics for completion of each of the grant objectives. While percent complete was not available for each of the objectives, Dr. Costa provided additional information regarding progress.

MOTION to approve continuation funding for Grant #CAUT14APL031 was approved with six members in favor, two recusals and one abstention.

Grant # CAUT15APL046

Voting for Grant # CAUT14APL046 *Piloting Very Early Electrophysiologic Markers for Risk of ASD and Related Disorders In Preterm and Low Birth Weight Infants* for year two funding was postponed until the March 2016 or June 2016 Council meeting to provide an accurate report of progress.

This grant was awarded in 2014 to Saint Peter's University Hospital and placed on hold shortly thereafter while awaiting transfer to Rutgers RWJMS. With the transfer complete the grantee is now establishing the infrastructure (staff, facilities, IRB) for the project.

Grant # CAUT13APS025

Dr. Eggerding called for a motion to approve Grant # CAUT13APS025, *Development of a new autism screening tool for traditionally underserved families* for year three continuation funding.

MOTION by Dr. Dreyfus to approve CAUT13APS025 for year three continuation funding was seconded by Dr. Friedman.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT13APS025 was approved with all members in favor.

Grant # CAUT12APS006

Dr. Eggerding called for a motion to approve Grant # CAUT12APS006, *Elucidating Genetic Components of Autism and Related Disorders* for year four continuation funding.

MOTION by Ms. Bell to approve CAUT12APS006 for year four continuation funding was seconded by Ms. Goldfarb.

Discussion: Dr. Costa presented an overview of the grantee's progress and recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve continuation funding for Grant #CAUT12APS006 was approved with seven members in favor and two recusals.

Grant # CAUT12ACC012

Dr. Eggerding called for a motion to approve Grant # CAUT12ACC012, *The Coordinating Center at Montclair State University (CC-MSU)* for year four continuation funding.

MOTION by Dr. Aquino to approve CAUT12ACC012 for year four continuation funding was seconded by Dr. Wang.

Discussion: Dr. Zanna presented an overview of the grantee's progress and recommended the grant be approved for continuation funding. A member noted the relatively low score for the Coordinating Center's impact on grantees' subject recruitment methods and materials as reported by the grantees. Dr. Costa described activities implemented since January 2015 when the data reflected in the report was collected during a meeting of the grantees. Another member

commented that she would expect to see increased collaboration with families since release of the January 2015 report ‘Summary of Findings from the 2015 New Jersey Autism Center of Excellence Grantee Survey’. Dr. Costa described specific outreach activities to families.

MOTION to approve continuation funding for Grant #CAUT12ACC012 was approved with all in favor.

VIII. NJ ACE Coordinating Center Update – Gerard Costa, Ph.D.

Dr. Costa presented a summary of the Coordinating Center’s activities and services. He announced the posting of two new positions, one for a biomedical consultant and the second for a behavioral consultant to provide expertise in the evaluation of grantees’ progress, as needed. Dr. Costa commented that the Coordinating Center continues to work with their consultant to refine the strategic plan for the current and next year of the grant. He briefly described the web-based platform being developed to streamline the progress reporting system. A member commented on the branding of the Coordinating Center as CC-MSU as a concern given the Council’s charge to fund the NJ Autism Center of Excellence (NJACE) with the Coordinating Center providing common management and support services. Dr. Costa addressed the concern and will make note for future notices and publications.

IX. Acting Executive Director Report- Martin T.Zanna, MD, MPH

Given that Dr. Zanna’s report was on past events and that the meeting was running later than anticipated, he preferred to send the report to members so that Dr. Eggerding had the time to provide the Council with an introduction to FY17 funding. The following report was sent to Council via email on September 24, 2015:

Thanks again to Dr. Eggerding for handling the introductions of our new members. As can be seen from their combined diversity of professional background and scientific expertise Council’s resource capacity has been significantly expanded.

I would further like to thank Rachel Hammond for joining us earlier during tonight’s meeting. There are many details that go into activating a new member to serve on this Council. Fortunately, since Rachel is an attorney as well as the Department of Health’s ethics officer, her availability to this Council ensures our members can seek guidance on any potential conflicts and any necessary recusals be implemented when indicated. Procedurally, this interaction enables members to remain in compliance with the state’s and the Council’s codes of ethics.

Events

Next, I would like to turn to two events occurring since our last Council meeting. On June 25, 2015 an event was held at Meridian Health Jersey Shore University Medical Center to

announce the new 2015 grantees. Participating in this event were First Lady Mary Pat Christie, DOH Commissioner Mary O'Dowd, Council Chair Caroline Eggerding, MD, and representatives from the host institution. Parents, Council member Dr. Aquino, DOH Director of Policy and Strategic Planning Cathleen Bennett and Dr. Gerard Costa and NJ ACE Coordinating Center staff were also present. Grantees representing the 3 newly funded Autism Medical Homes were present—Dr. Jill Harris and Dr. Matthew McDonald (Children's Specialized Hospital); Dr. Stephen Kairys (Meridian—Jersey Shore University Medical Center, Neptune); and Dr. Randy Huron (Meridian—Hackensack University Medical Hospital). Additionally, Dr. Deborah Spitalnik (the Boggs Center, Rutgers University) was present. This funding cycle featured Council's grant awards totaling \$4.4 million to establish Autism Medical Homes as well as fund clinical and clinical translational research pilot projects (\$1.2 million for the 3 Autism Medical Homes and \$3.2 million for 8 clinical and translational research pilot projects). Mrs. Christie and Commissioner O'Dowd met privately with families prior to the award ceremony which added a personal touch to the event. The First Lady talked about the administration's current commitment to create greater awareness about autism in NJ and its desire to support parents to help children lead full/productive lives. The 3 Autism Medical Homes pilot projects are designed to improve health outcomes for children with ASD. The project's goal is to improve the quality of and access to services along the continuum of care.

The September 18, 2015 New Jersey Autism Center of Excellence Summit 2014 titled "The Unfolding Story of Autism Research in NJ From Cells to Society" was well received. The event held at Montclair State University included 14 presentations by grantees in a morning and afternoon panels. Grantees making presentations during the panels were Drs. Brzustowicz, Comoletti, DiCicco-Bloom, Feeley, Janvier, Kerwin, Jyonouchi, Learmonth, Millonig, Mintz, Stein, Torres, Zahorodny, and Zimmerman-Bier. With the new grantees receiving awards this past June, we now have 27 active grants plus the Coordinating Center. The audience at the event included over 225 participants representing researchers, policy makers, providers, and family members. Dr. Costa in the afternoon gave a vision for the next Summit (to be held in 2017). The final afternoon panel addressed questions raised by audience participants. Dr. Michael Lewis moderated the conference and the Keynote Speaker was Dr. Willis Overton (from Temple University) whose keynote was titled, "Research Begins with Questions and Implicit Assumptions: How May this Impact Autism Research?" The meeting program included a welcome letter from Governor Christie.

The event was covered by:

NJ TV news reporter Briana Vanozzi
Montclair State Univ. News
CNBNews.net
NJ Spotlight

The meeting was video recorded and will be available for future reference.

Also in attendance were:

Council members:

Liz Bell

Caroline Eggerding, MD

Cheryl Dreyfus, Ph.D.

Department of Health staff:

Anthony Welch, Director of Policy and Strategic Planning

Sandra Howell, PHD (autism registry)

Nancy Scotto Rosato, PHD (autism registry)

Daphne Robinson, PHD, and myself

Acting Commissioner Cathy Bennett's presentation was very supportive of the work of the Council under the leadership of Dr. Eggerding and the role of the NJACE Coordinating Center. She stressed the administration's support for Autism clinical research and expansion of the autism medical homes by inclusion in the RFA released September 9, 2015 an emphasis on transition issues of adolescents/young adults.

Organizational Changes

Next, I would like to mention DOH organizational changes. Cathleen Bennett (formerly Director Office of Policy and Strategic Planning) is now Acting Commissioner, NJ Department of Health. Taking Cathy Bennett's place as our new "boss" is Anthony Welch who comes to the DOH from the Governor's Office where he was a Senior Policy Advisor.

Also, another organization change for Council's office is the creation of a new position-- Quality Assurance Specialist, Health Services, Nursing. If all goes well, we would like to hire into this position by November 1 at the latest. Given the proliferation of number of grantees and the complexity of the scope of the Coordinating Center, this position will enhance our ability to monitor grantee's performance.

Scientific Advisory Committee (SAC) member changes: last March, Stewart Mostofsky, MD (a pediatric neurologist at Kennedy Krieger Institute at John Hopkins, Baltimore) announced his departure from the SAC. Taking his place is Alex Paciorkowski, MD, PHD also a pediatric neurologist based at the University of Rochester Medical School in Rochester, New York.

RFA SFY' 16

The SFY'16 was released on September 9, 2015. The RFA was discussed with Cathy Bennett prior to finalization and is fairly similar to the SFY 15 RFA by including clinical research and

clinical translational research, as well as Autism Health Needs Medical Homes. A major difference of this RFA is that the RFA with respect to the Autism Health Needs Medical Homes includes language that the state is interested in projects that address adolescents to young adults (transitions to adulthood). We are making changes/modifications to the SAGE system so that all applications and reviews will be on-line. The earlier date for release of the RFA (September 9, 2015) was decided upon in order to give state staff sufficient time to process the applications and conduct the three review panels: Biomedical clinical research/translational research, behavioral related clinical research, and autism health needs medical homes health services research/pilot projects.

Application timelines are as follows: Letter of intent due November 11, 2015, applications due December 12, 2015, announcement of awards June 1, 2016. Between the receipt of applications and the announcement of awards, Council staff reviews applications for compliance with DOH policies, recruits reviewers, assigns applications to reviewers with expertise specific to the applications, conducts three review panel meetings via teleconferences, reviews borderline applications with the SAC, finalizes recommendations, provides summary of review panel meetings and access to SAGE for the Council to review applications and critiques. Council votes for funding and the grants are then processed through several offices within the DOH.

Annual Report

The 2014 Annual Report was approved by the DOH and is posted on our website. I would like to thank Caroline for reviewing the report as well as thank Linda Bocclair for her efforts to finalize the annual report.

X. Preliminary discussion of plans for FY17 funding

Dr. Eggerding described the Council's role in funding autism programs, noting the Council is "in and of" the NJ Department of Health (NJDOH) and, as such, makes funding recommendations to the NJDOH. In the process of moving the Council from the UMDNJ to the NJDOH in 2007 six Clinical Enhancement Centers (CECs) were funded in 2008. Strategic Planning resulted in the NJ Autism Center of Excellence Coordinating Center funded in 2012.

Decisions must be made for programs to be recommended for funding in FY17. There will be a discussion of the Council's Establishing Legislation, [P.L.2007, c.168](#) at the December 7, 2015 Council meeting to decide which mandates have been met and others that are outstanding, resulting in recommendations for FY17 funding. Background information will be sent to members in preparation for the meeting.

Members discussed the following:

- History of Council funding including funding mandates as per the P.L.2007, c. 168 and the evolution from 5 year program site grants to 2 year translational and clinical research pilot grants with the recent addition of medical homes models (Autism Health Needs Medical Homes grants).
- The need to consider advances in autism research since the passing of the 2007 Legislation P.L. 2007, c. 168 and to understand that the Legislation limits options for funding to the stated mandates.
- The need to build strong research in New Jersey through collaborations and other means.
- Potential programs to fund in FY17, including but not limited to basic and translational/clinical research; education to inform the general public, policy makers and other stakeholders of the advances (body of knowledge) in autism research nationally; research projects to address the needs of young adults as they “age out” of services; and establishment of a state-of- the-art medical model of care for individuals with ASD.

Conclusion: In preparation for the December 7, 2015 Council meeting members will be sent copies of the Establishing Legislation and the 2012 report by Rutgers University Center for State Health Policy entitled *Needs Assessment to Inform the Development of a Strategic Plan for the Governor’s Council for Medical Research and Treatment of Autism: intended to guide Council’s strategic planning.*

XI. Report of Revenues and Expenditures

The report was included in members’ Council packet for their information. Due to the lack of time this agenda item was not discussed.

XII. Adjournment

Dr. Eggerding asked for a motion to adjourn.

MOTION to adjourn by Dr. Dreyfus and seconded by Ms. Spett was approved with all in favor.

The meeting was adjourned at 9:10 PM.